Parenting After the NICU: Prioritizing Perinatal Mental Health and Family Well-Being

Today's goals

- Understand challenges families face when an infant requires NICU care and transitions home
- Identify strategies to strengthen parent-child relationship to integrate into interactions with families
- Describe the efforts of Hospital-to-Home Systems Change work

Presentation

- **Overview of terms and language used in presentation**
  - NICU — Neonatal Intensive Care Unit
  - ESIT — Early Support for Infants & Toddlers (Part C of IDEA services in WA State)
  - Perinatal — Refers to the time from conception through one year postpartum
  - PMADs — Perinatal Mood and Anxiety Disorders
  - PFD — Pediatric Feeding Disorder (feedingmatters.org)
  - Use of "caregiver" and "parent" will be interchangeable to recognize non-biological parenting roles, acknowledge not all birthing individuals identify as women or mothers
  - Hospital-to-Home (H2H) Care Model — an interdisciplinary approach to ESIT services for infants discharged from the NICU, integrating support for parents' perinatal mental health with therapeutic support for infants' feeding, growth, and development
- **Landscape**
  - Reasons infants might need NICU level care
  - Preterm birth disparities based on ethnicity and also geography (March of Dimes)
  - Maternal healthcare deserts as proxy for neonatal healthcare deserts
  - Neonatal levels of care map
- **Psychosocial Challenges for NICU parents**
  - NICU babies are fragile and need their parents' engagement and encouragement to develop and thrive. Their parents need the same level of loving kindness and skill building help to grow and thrive as new parents
- **Obstacles to Successful Bonding/Attachment & Development**
  - *Infants* – medical intervention, not relationships; fragility; medical touch, not loving touch; unable to use "typical" attachment behaviors; unable to offer regulating function for parent
  - *Caregivers* – expectations vs reality; attachment vulnerabilities magnified; lack of emotional engagement; inability for typical parenting behaviors that build role and relationship
- **Obstacles to Learning to Read Medical Cues instead of "Learning Your Baby"**
  - Learning to "read" staff for cues about how your baby is doing. "Med-speak" not baby talk.
  - Variety of machines for YOUR child AND other people's children. Hyper-vigilance.
  - Machines are lifesaving AND interrupt the natural development of parent-infant relationship.
  - Anxiety of going home without medical support.
- **Perinatal Mood and Anxiety Disorders (PMADs)**
  - Heightened risk–increases with frayed attachment and high rates of PMAD disrupt attachment
  - What are PMADs? - https://www.postpartum.net/perinatal-mental-health/
  - *PTSD* – NICU itself may be traumatic event separate from and in addition to other birth-related traumas. Rates of PTSD in parents from - 4.5% - 30% (McKeown et al; 2022)
  - *Depression* – NICU mothers had 74% higher risk of developing PPD, general population PPD increased 3-fold during pandemic (Shuman et al; 2022), BIPOC and marginalized groups with marked increase

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- *Anxiety* – NICU mothers show anxiety range 18-43%, Recent study just under half of parents in NICU level 4 showed clinically significant levels of anxiety or depression

- **Parent Role Development**
  - Parents require proximity, frequent interactions, and successful completion of behaviors consistent with (pre-existing) images of "good parenting"
  - Becoming a parent in the NICU requires building parental identity on a very different basis-new and never imagined tasks must be mastered in context of emotional distress, trauma, and grief
  - **Perinatal Mental Health Resources**
- **Why this Matters?**
  - By the time a family arrives on your doorstep, it is 80% likely that one or both parents suffer from PTSD or postpartum depression or anxiety, may be grieving loss of "normal"
  - Respectful acknowledgement and proper labeling of the difficulties endured will typically help parents regain some sense of efficacy and enhance connection to baby
  - Others (NICU, peds, OB) may not have mentioned PMADs and/or provided resources for psychological support
- **Challenges of being home post-NICU**
  - *Social* – discomfort in role as caregiver, isolation & grief, distrust, future filled with unknowns
  - *Economic* – financial pressure, lack of childcare options
  - *Physical* – birth recovery, health exposure concerns
  - *Logistical* – home not set-up for medical equipment, difficulty navigating follow-up
  - *Risk factors* – infants at risk for feeding concerns and/or development delay; caregivers at risk of experiencing PMADs
- **Addressing the Service Cliff: What can we do?**
  - Timely referral and provision of services is critical
  - ESIT and home visiting programs are shown to reduce parental stress, improve attachment, support better infant health outcomes.
  - Supported transitions may reduce overall medical expenditures
  - Important to consider health impact of color, limited English proficiency, financial strain
- **Early Support for Infants & Toddlers (ESIT)**
  - What is ESIT?
  - Learn more: https://dcyf.wa.gov/services/child-dev-support-providers/esit
  - Resources on website include: statewide directory, information for healthcare providers, qualifying diagnoses, families needing help can call WithinReach HelpMeGrow 800-322-2588
- **Hospital-to-Home Program Care Model**
  - Community-based infant feeding & developmental therapy can support caregivers' emotional well-being by providing therapy in natural environment (e.g., home), offering family-centered care, connecting families to community resources
  - H2H Care Model – Care Continuum
    - Specially trained, interdisciplinary team
    - Rapid follow-up post discharge
    - Understanding and supporting perinatal mental health
    - Clear communication with families and medical providers
- **Feeding and attachment considerations**
  - Parents equate their parenting success to ability to feed their baby
  - Infant stable and still learning
  - Evolution of feeding goals

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- Support caregiver with intentional engagement

- **Feeding and emotional well-being are connected**
  - Perinatal mental health impacts attachment, development, and ability to implement feeding strategies including learning, understanding, and using feeding skills
  - Also impacted: Interactions and ability to read, respond and respect infant's cues
- **Caregiver support**
  - Create space
  - Parallel process
  - Respectfully respond to emotions using NURSE (Naming, Understanding, Responding, Supporting, Exploring) https://www.vitaltalk.org/guides/responding-to-emotion-respecting/
- **Hospital-to-Home Systems Change**
  - Mission/Goals:
    - Address the barriers, gaps in care, and inequities that exist for infants and caregivers transitioning from hospital into ESIT and community therapy services throughout the state
    - Effort to build the capacity of the workforce to support the Hospital-to-Home population
  - Tenets all upon foundation of perinatal mental health
    - *Hospital* – understand landscape and connect with referral sources: education, support
    - *Home* – build workforce capacity, develop community of practice, consultation
    - *Advocacy* – presentations, convening PMH task force, supporting state-wide change
  - Training Efforts
    - *3-day training* – PMH (foundational), PFD in infants, Special topics & Parent voice
    - *Project ECHO series* – PMH, "all teach, all learn" model
- **Closing Remarks**
  - What can you do to prioritize perinatal mental health and family well-being?
    - *Presence* - sit with
    - *Listen* - to caregivers
    - *Collaborate* - seek opportunities to connect and partner
    - *Reflect* - on ways to integrate support for the emotional well-being of parents into the work already being done
    - *Advocate* - for systemic changes that best support the needs of infants and caregivers
    - *Make* - small changes, they can lead to bigger changes
- **Questions & Answers**

Contact Us

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www.hospitaltohomesystemschange.org

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